

July 2016

The Kansas State Plan for

# Systems of Care for Children and Youth with Special Health Care Needs



Completed by the Kansas Special Health Care Needs Program  
*in consultation with EnVisage Consulting, Inc.  
the Kansas University Center for Public Partnerships and Research,  
and the Wichita State University Community Engagement Institute*

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## Overview

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Children and youth with special health care needs (CYSHCN) are a diverse group of children defined, by the Department of Health and Human Services Maternal and Child Health Bureau, as “children birth to age 21 who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.” This can range chronic conditions such as asthma or diabetes, to developmental disabilities such as Down syndrome or autism, to medically complex health issues such as spina bifida or other congenital disorders, to children with behavioral or emotional conditions. The Kansas State Plan for Systems of Care for CYSHCN is intended for agencies and organizations serving CYSHCN and stakeholders, including parents, caregivers, and individuals, in supporting Kansas to achieve the *Standards for Systems of Care for CYSHCN* (referred to as “Standards” throughout this document) to strengthen collaboration, support systems integration and improve service delivery for CYSHCN.

The Kansas Department of Health and Environment, Special Health Care Needs (KS-SHCN) Program, as part of the Title V Maternal and Child Health Block Grant, is dedicated to building capacity, infrastructure, and support systems of care for CYSHCN to assure children and their families receive services that are accessible, continuous, comprehensive, coordinated, compassionate, culturally competent and family-centered. As a state program, KS-SHCN promotes the functional skills of persons, who have or are at risk for a disability or chronic disease, providing specialized medical services to infants, children and youth up to age 21 who have eligible medical conditions. Additionally, the program provides services to persons of all ages with metabolic or genetic conditions screened through the Newborn Screening. Services may include diagnostic evaluations, treatment services or care coordination.

In order to fully achieve a comprehensive system of care, improving health outcomes, it is critical to recognize that all children have the potential for having a special health care need at some point in their life. Therefore, the framework provided by the *Standards* includes components that are not only relevant to CYSHCN, but to the general child population. Over time, it has been noted that creating a comprehensive, quality system of care for CYSHCN has been a challenging endeavor, especially stakeholders such as state Title V CYSHCN programs, health plans, private insurers, state Medicaid and CHIP agencies, pediatricians and family physicians, and families. For decades, state and national champions have advocated for the development of a framework or set of standards or measures to support a comprehensive system of care for CYSHCN and their families. The *National Consensus Framework for Improving Quality Systems of Care for Children and Youth with Special Health Care Needs* project was created to develop such a set of standards. The development of the *Standards* were strategic, evidence-based/evidence-informed, and engaged a diverse group of national stakeholders. These standards are based on a comprehensive review of the literature, key informant interviews, case studies of standards for CYSHCN currently in use in Title V, Medicaid and health plans within selected states and consensus from the national work group. A detailed description of how the standards were developed available by clicking here or visiting <http://www.amchp.org/AboutAMCHP/Newsletters/member-briefs/Documents/Standards%20Charts%20FINAL.pdf>.

These *Standards* are intended for use by a range of national, state and local stakeholder groups including state Title V CYSHCN programs, health plans, state Medicaid and CHIP agencies, pediatric provider organizations, children’s hospitals, insurers, health services researchers, families/consumers and others. The *Standards* are designed to supplement, not substitute, federal statute and regulatory requirements under Medicaid, the ACA and other relevant laws.

## ■ ■ The Role of Title V

The Kansas Department of Health and Environment (KDHE) is responsible for the administration of programs carried out with allotments under Title V. The Title V Maternal and Child Health (MCH) Services Block Grant program is administered by the Bureau of Family Health (BFH) in the Division of Public Health. The mission of the Bureau is to “provide leadership to enhance the health of Kansas women and children through partnerships with families and communities.” KDHE convenes the Kansas Maternal and Child Health Council and contracts with local public health departments (independent entities) across the state to ensure coordination of MCH services within a coordinated, family-centered system.

The Title V mission is to improve the health and well-being of the nation’s mothers, infants, children and youth, including children and youth with special health care needs, and their families. Title V legislation and the MCH Service Block Grant Program enables states to: a) provide and assure mothers and children access to quality MCH services; b) reduce infant mortality and the incidence of preventable diseases; c) provide rehabilitation services for blind and disabled individuals; and d) provide and promote family-centered, community-based, coordinated care, and facilitate the development of community-based systems of services.

Title V is responsible for promoting the health of all mothers and children, which includes an emphasis on CYSHCN and their families and the development of life course theory has indicated that there are critical stages, beginning before a child is born and continuing throughout life, which can influence lifelong health and wellbeing. To assist with planning how to achieve these objectives, the Kansas Title V conducted a Five Year Needs Assessment (2016-2020) process utilizing a mixed methods approach relying on continuous input from a diverse team of key informants, partners, and community members as well as broad public input. This comprehensive process and broad approach assisted with identifying key priorities to ensure an intended plan of action to effectively improve and address maternal and child health. The Kansas Title V needs assessment resulted in eight state priorities, selected with the Title V mission, purpose, legislation, and measurement framework in mind.

1. Women have access to and receive coordinated, comprehensive care and services before, during and after pregnancy
2. Services and supports promote healthy family functioning
3. Developmentally appropriate care and services are provided across the lifespan
4. Families are empowered to make educated choices about nutrition and physical activity
5. Communities and providers/systems of care support physical, social, and emotional health
6. Professionals have the knowledge and skills to address the needs of maternal and child populations
7. Services are comprehensive and coordinated across systems and providers
8. Information is available to support informed health decisions and choices

Of these state priorities, Priority 7 is assigned to the CYSHCN MCH domain, however it addresses all children in the way that KDHE strives to provide services: comprehensively and inclusively. As a Title V program, one of the main goals of KS-SHCN is care coordination, so that children and their families can navigate systems to gain optimal health in a consistent and comprehensive way. Throughout the Needs Assessment process, it became apparent that family support was emerging as a high need and that those supports include access to care (transportation, especially in rural communities, and providers who will treat CYSHCN especially oral health). As the assessment progressed family support also expanded

into the need for social-emotional support and respite for caregivers. Providers were also a high need given many are not specialists and many do not practice near rural communities. Family-centered medical homes need support and partnerships can be explored based on the needs presented. This can include existing structures that KDHE can support as well as engaging MCO's and primary care providers, implementing tele-medicine, and professional development training. This priority exemplifies the collaboration and partnership building principles that KDHE promotes and is willing to sustain so that all children with health care needs are children first.

## ■ ■ Key Partners

Thank you to each and every partner who provided input, feedback, and support during the development of this plan!

A special thanks to Envisage Consulting, Inc. and the Kansas University Center for Public Partnership and Research for their support throughout the KS-SHCN Strategic Planning process. This process was the catalyst to developing this type of a statewide plan.

A special thanks to Wichita State University for their facilitation, leadership, analysis, and support throughout the state plan development activities. Without this support, this plan (and the stages to come) would not be possible.

A special thanks to the Leadership Team who developed the process utilized during the state plan development. The Leadership Team:

Heather Smith	Director, Special Health Services
	Bureau of Family Health, Kansas Department of Health and Environment
Kayzy Bigler	Program Manager, Special Health Care Needs
	Bureau of Family Health, Kansas Department of Health and Environment
Traci Reed	Director, Children and Families
	Bureau of Family Health, Kansas Department of Health and Environment
Ingrid Larson	Pediatric Nurse Practitioner
	Children's Mercy Hospitals
Samantha Ferencik	Program Analyst
	Division of Health Care Finance, Kansas Department of Health and Environment
Donna Yadrich	Family Leader
	Special Health Services Family Advisory Council
Chris Steege	Executive Director
	American Academy of Pediatrics, Kansas Chapter
Erick Vaughn	Executive Director
	Kansas Head Start Association

Other contributing partners consisted of family members, local health departments, managed care organizations (insurers), hospital partners, medical and mental health providers, early-intervention providers, universities, home health

care providers, developmental disability organizations, federally qualified health centers, early childhood educators, and other community organizations.

## Summary of Strategic and State Plan Meetings

### ■ ■ KS-SHCN Strategic Planning

In July 2013, KS-SHCN began an extensive strategic planning process including a series of meetings with key stakeholders, surveys, community meetings, and input from the Special Health Services Family Advisory Council (SHS-FAC). The strategic planning began as an opportunity to assess the state program on the following metrics:

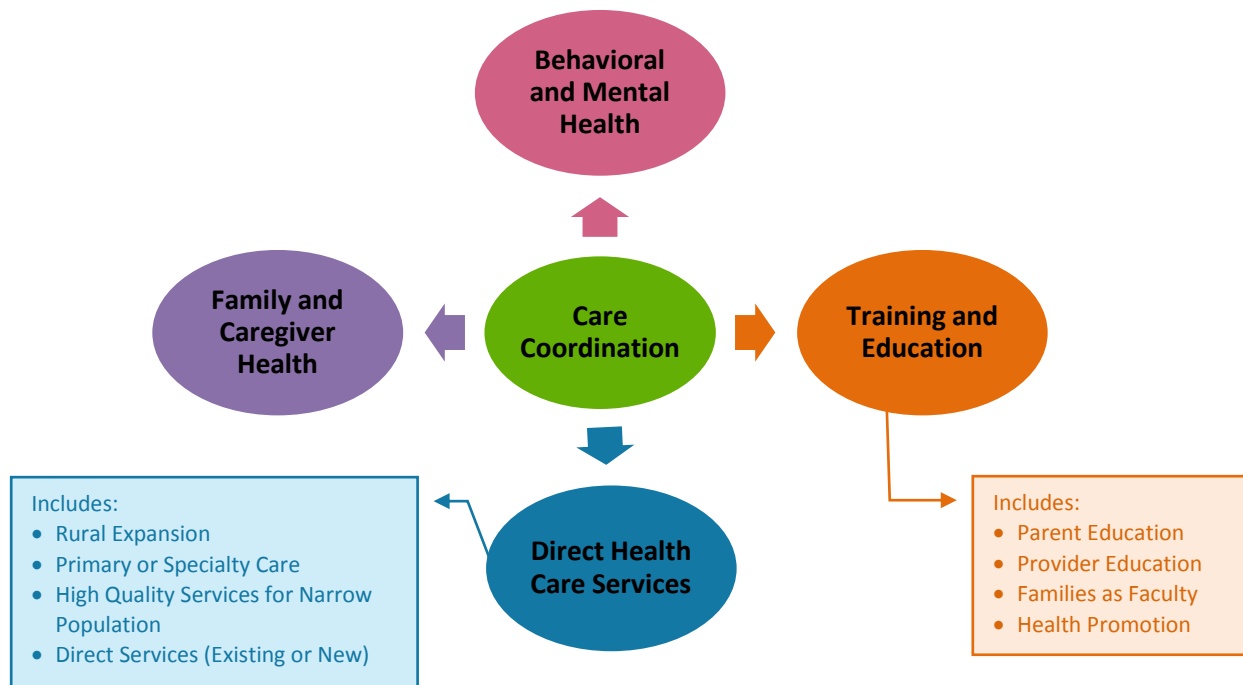
1. Increasing the value of the program for those served  
*Identified through qualitative data collected through stakeholder input sessions.*
2. Evaluating relevancy of program services offered for families  
*Identified through analysis of existing direct service and clinic service provision data.*
3. Evaluating cost-effectiveness of direct and clinical services  
*Identified through a cost-analysis of all funding sources, including contracts and clinical services.*
4. Identifying opportunities for improvement and alignment with state and federal programs  
*Identified through utilizing quality improvement methodology, statute and regulation review, and the Transformation of the Maternal and Child Health Block Grant, aka “MCH 3.0.”*

Early in the process, it was clear that a need shift was needed in the services provided, policies and procedures, and accountability of subcontracted partners. This shift in the “way of doing business” required extensive review and evaluation prior to making changes within the program. This document will provide an overview of the strategic planning process, outcomes and expected changes, and next steps for the KS-SHCN Program.

The initial phase of Special Health Care Needs (SHCN) Strategic Planning involved a group of staff and clinic partners and a group of family leaders meeting in July and August of 2013. Each group identified five policy priorities for consideration.

Professional Priorities	Family Leader Priorities
1. Care Coordination	1. Care Coordination
2. Parenting Education (focus on financial counseling, effective advocacy, partnering with providers)	2. Families as Faculty Program (focus on provider knowledge of SHCN needs and family impact)
3. Behavioral and Mental Health	3. Family and Caregiver Health
4. Focus on High Quality Services for a Narrowed Population	4. Expansion of All Service Systems to Rural Communities
5. Primary Medical Care Coverage	5. Behavioral and Mental Health

Two priorities, Care Coordination and Behavioral/Mental Health, overlapped the two groups. Other priorities had similarities, resulting five priority issues presented for in-depth consideration at the second phase of the strategic planning.



The second phase of the strategic planning engaged stakeholders, including community organizations and agencies, and family leaders in conducting an analysis of the current systems’ strengths, weaknesses, opportunities, and threats (a.k.a. a SWOT analysis) and identifying gaps within the system. The SWOT and Gap analyses provided necessary information throughout the planning process about resources and the current capacity of those resources to serve families. Additionally, key concepts and themes emerged, to assist in the development of overall objectives and strategies in the third phase of the strategic planning process. Key concepts are outlined on the next page.

### Care Coordination

- **Treat the whole family**, not just the child, but all of those components – child care for other kids, transportation to appointments, coordination of services, parent support, teaching training, parent physical & mental health, recovery issues, coordinating all the coordinators
  - Health care system trains you to focus on specific medical problem, but families have to focus on life
  - Develop relationships with the families
  - Understand that the child’s problem affects the family as well: need to educate, simplify the system, focus on relationships
- **Increase awareness** of available resources; still a lack of awareness about what’s available



- **Improve care** statewide, particularly at the **local level and in rural areas**. Suggested two-pronged approach:
  - **Provide care regionally** (Garden City, Hays, Salina), not just in Kansas City and Wichita.
  - **Connect regional and local providers with national experts** on certain medical conditions to help access most current, evidence-based practices and services.
  - **Simplify the system**. Maximize the benefits of care coordination without letting these activities become burdensome or duplicative. **Clearly define roles and scopes of providers, organizations and programs** to fill gaps and maximize coordination while minimizing overlaps and avoiding unnecessary bureaucracy.

### Behavioral and Mental Health

- **Need pre- and post- transitional services** for multiple transition points
- **Psychiatric Residential Treatment Facilities (PRTFs)** have limited capacity and other gaps
- **No routine early intervention or screening process** for behavioral or mental health; wait too long to identify problems
- **Need ability to bill without a specific diagnosis**
  - Allow parents to reach out, access services, get questions answered without having to fear a label
- **Lack of community services**, need consistency
- **Respite care**

### Family and Caregiver Health

- Biggest gap is **lack of awareness** of what is currently available. Both providers and families lack awareness of available resources.
- **Improve support for families. Family is an integral part of the plan.** How can the family be healthy to sustain the child's health? Infant toddler does a nice job with this, but this approach doesn't really continue as the child grows up.
  - If child is diagnosed after the age of 3 years, the family doesn't really ever get those services.
  - **Is there a way to pay families who provide care to children that is over and above what they would normally be expected to do** – would actually save funds overall *and* impact poverty. Poverty is a big predictor of family health issues. Also, is family reimbursement available for caregiving if child is over 18 years?
- Find assistance and resources for children who do not qualify for services but still have needs.

### Training and Education

- Increase awareness of available resources; **educate providers and communities about Families Together**
- Consider policy direction regarding training and education standards; in particular, **need requirement for the care of CSHCN among licensed providers** (hospitals, nurses, physician assistants, dental hygienists, etc.)
- Educate people in all the places where children are; **train community members and organizations how to respond to and ensure safety** (at a minimum) of children with special health needs; this includes teachers, child care providers, fire, police, etc.

### Direct Health Care Services

- **Lack of pediatricians and specialists** in the state of Kansas
- Need to market for and **increase awareness of the services that the SHCN program** provides



- **Need effective regionalization**, resulting in more services and increased capacity regionally (beyond Kansas City and Wichita)

Upon completion of this analysis, the SHS-FAC reviewed each priority and the related key concepts and drafted the following definitions around each priority.

<b>Cross-System Care Coordination</b>	“Patient and family-centered approach that utilizes team-based and assessment activities designed to meet the needs of children and youth while enhancing the capabilities of families. It addresses interrelated medical, behavioral, educational, social, developmental, and financial needs to achieve optimal health.”
<b>Behavioral Health Integration</b>	“Collaborative services for the prevention and treatment of emotional disorders that support the functioning of children, youth, and families in all settings, including home, community, school, and work. Efforts should be focused on keeping children in their home and/or community.”
<b>Family Caregiver Health</b>	“Supporting the physical, emotional, social, and financial well-being of families with CYSHCN, particularly that of the family caregivers. A family caregiver is any individual, including siblings, who supports and cares for another person and may or may not be a biological relative.”
<b>Training &amp; Education</b>	“Supporting diversity in the provision of services for the special health care needs (SHCN) population through training and education of families, community members, medical and community providers, local and state service programs, and legislators. This includes family and youth leadership development in building a stronger advocacy network in Kansas.”
<b>Direct Health Services and Supports</b>	“Services delivered one-on-one between a health professional and patient, which may include primary, specialty, or ancillary health services, such as: inpatient and outpatient medical services, allied health services, drugs and pharmaceutical products, laboratory testing, xray services, and dental care. Access to highly trained specialists or services not generally available in most communities may also be included in this definition.”

The third phase of the strategic planning process was designed around the development of objectives to address the five new priorities of the KS-SHCN program. Stakeholders were convened for a final planning meeting to review the analysis from phase 2 and the definitions providing guidance by the SHS-FAC. The group worked together to draft objectives for each priority. Upon completion of the objectives, internal discussions ensued to create strategies and measures to guide the work. The strategies were approved by the SHS-FAC and integrated into the overall Title V 2020 State Action Plan. Overall, KS-SHCN developed a robust action plan, with 5 priorities and a total of 14 objectives and 31 total strategies. The complete KS-SHCN 2020 Strategic Plan can be found in Appendix A.

## ■ ■ Standards for Systems of Care for CYSHCN

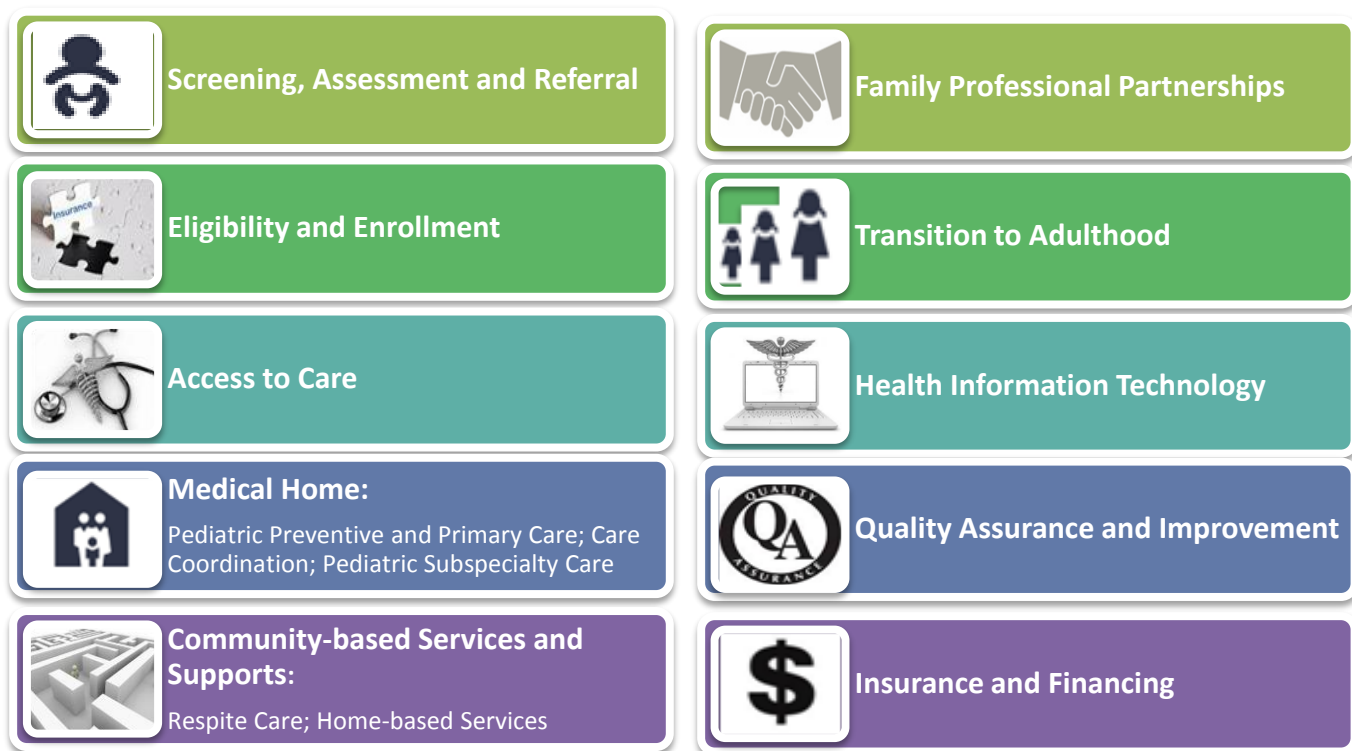
One purpose of the KS-SHCN strategic planning was to align program services and contractual supports with the “Standards for System of Care for Children and Youth with Special Health Care Needs.” This began with the strategic planning, however has been enhanced with the KS-SHCN 5-Year Plan and KS-SHCN continues to build infrastructure and capacity for increased services for all CYSHCN in Kansas.

In September 2015, KS-SHCN was awarded a two-year grant awarded to support access for CYSHCN to receive services through an accessible, continuous, comprehensive, coordinated, compassionate, culturally competent, and family-centered medical home. Fragmented service delivery systems for Kansas CYSHCN are difficult to access or navigate for many families. An estimated 120,822 CYSHCN represent 17.3% of the overall KS child population, ages 0-17. CYSHCN often have unmet needs, inadequate insurance, do not experience family-centered health care, and go without a usual source of sick or well care. This is a particularly for those who are at risk to, or may, endure access issues because they: 1) reside in rural and frontier communities; 2) experience barriers due to disability or language needs; and 3) are uninsured or underinsured.

Through quality improvement and evaluation, we strive for improvement and increased system capacity to provide these services to all families of CYSHCN, particularly those who are at risk to, or may, endure access issues because they reside in rural and frontier communities, experience barriers due to disability or language needs, or are uninsured or underinsured. The “State Implementation Grants for Enhancing the System of Services for CYSHCN through Systems Integration” grant identifies four primary goals:

1. Develop a multi-system state plan that supports system standards and enhanced services for children and youth with special health care needs.
2. Develop integrated partnerships across systems to support children and youth with special health care needs and their families.
3. Establish community partnerships to support expansion of and long-term sustainability of a shared resource.
4. Assure children and youth with special health care needs have access to care coordination services and supports that engage families in shared decision making and encourages feedback on services received.

More information about the grant objectives and the connection with this State Plan can be found in the following section, however it should be noted that all activities under this grant are being aligned with the *Standards*, outlined in further detail in the overview section and Appendix C. This section will outline how these standards are being integrated into KS-SHCN and Title V activities and provide framework as to the purpose and intent of this state plan. However, this plan encompasses much more than the KS-SHCN or Title V systems, and it is desired the plan will include each of the ten Standards domains and system partners serving CYSHCN within these domains.

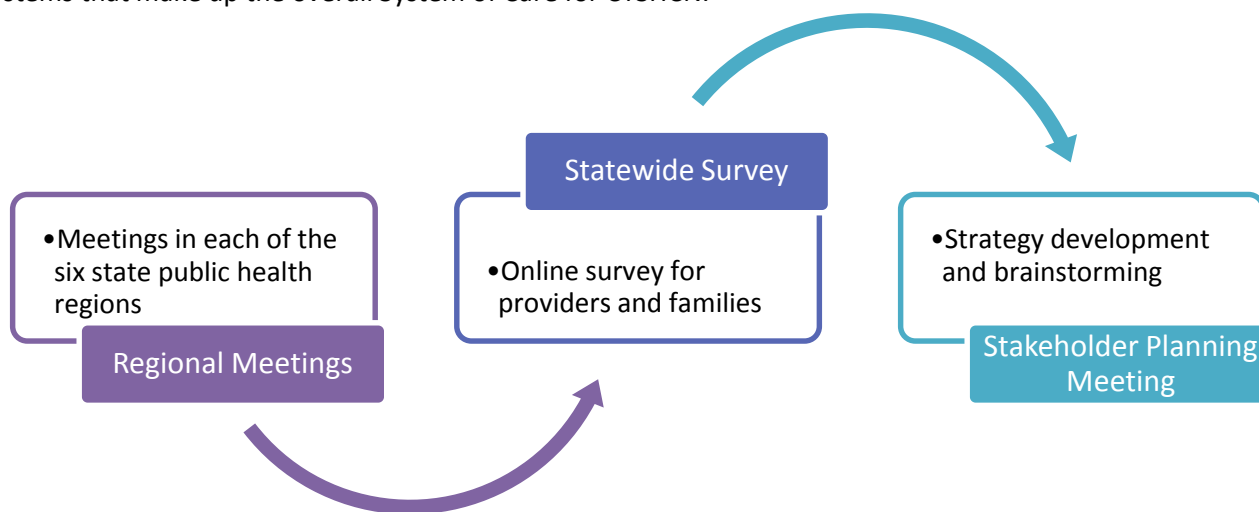


Throughout the development of these standards, national stakeholders and key informants provided information about the existing system of care and identified key themes. More detail about these can be found in Appendix D, *Developing Structure and Process Standards for Systems of Care Serving Children and Youth with Special Health Care Needs: A White Paper from the National Consensus Framework for Systems of Care for Children and Youth with Special Health Care Needs Project*. The following is an excerpt from this document to highlight some of the key themes and provide context as to how the above domains were created.

- A need for and potential role of standards to strengthen systems of care for CYSHCN was acknowledged.
- CYSHCN need to be considered in current health service delivery reforms in states.
- System standards should promote and foster systems integration within health care delivery systems and other child-serving systems.
- Standards should build on existing national frameworks for CYSHCN.
- Standards for CYSHCN should be aligned with existing adult health care standards.
  - Focus standards on the system components rather than condition specific issues, such as: care coordination and medical home; access to care; cultural competence; family-centered care; transition; and information technology and safeguards, including Electronic Health Records.
- Standards should address identification and screening of CYSHCN and issues of difficult transitions between coverage types.
- Efforts to promote quality measurement and improvement to address health outcomes should be considered in the development of standards.

As stated above, one of the goals of this grant is to “develop a multi-system state plan that supports system standards and enhanced services for children and youth with special health care needs.” While KS-SHCN supports this effort and believes a plan of this nature is highly needed to continue working towards integrated systems and collaboration, the development of this plan was a requirement of the federal grant funding. Therefore, KS-SHCN set out to develop a state plan that would meet the needs of the overall system of care, rather than simply developing a plan to meet the grant objectives.

Due to the extensive nature of this plan, the plan is being developed in stages over the course of two years. It is believed this will allow for sufficient review and assessment of each domain and the related standards, utilizing a community engagement process and engaging the most appropriate partners for each domain. Each stage will utilize the same process, see diagram below, with the ultimate objective being a plan that includes a shared vision and ownership among all systems that make up the overall System of Care for CYSHCN.



Through the qualitative data received through the regional meetings, the quantitative data received through the survey, and the strategies presented at the planning meeting, each stage will ultimately create a shared vision for the domains discussed.

- This first stage began in February and concluded in May 2016 and focused on the Medical Home and Community-Based Services and Supports domains, as they were the most relevant to the grant and assisted in the development of this first version of the Kansas State Plan.
- The second stage will begin in August and conclude in October 2016 and focus on the Screening, Assessment, and Referral and Eligibility and Enrollment domains.
- The third stage will take place February through May 2017, focusing on Access to Care, Family Professional Partnerships, and Transition to Adulthood.
- The final stage will occur August through October 2017 focusing on the final three domains: Health Information Technology, Quality Improvement, and Financing.

## ■ ■ State Implementation Grant for Enhancing the System of Services for CYSHCN

States participating in the “State Implementation Grants for Enhancing the System of Services for CYSHCN through Systems Integration” are working to increase the proportion of CYSHCN who receive integrated care through a patient-centered medical home or health home approach. To do so requires states to form collaborative partnerships across agencies, organizations and programs and to coordinate the policy and programs developed to ensure CYSHCN receive the comprehensive services and supports needed. This includes the development of a state plan and implementation of three common cross-state strategies for the grant projects:

1. Development or expansion of a shared resource;
2. Integration of care for CYSHCN with the goal of working towards creating a comprehensive system of care for CYSHCN; and
3. Strategies to improve cross-system care coordination.

State grantees collectively created and “Aim Statement” and a series of “Drivers” for each of the strategies listed above. In addition, states were asked to develop a common measure for each of the Aims to be used to evaluate the impact of different state activities on these strategies over the course of the project. Highlights of these are outlined below, however a Driver Diagram – describing each of these components and the overall plans of the Kansas grant are available in Appendix E.

**Integration Strategy Aim Statement:** By October 2017, an agency-level written agreement will be developed between two or more state or regional-level entities to improve the timely receipt of information following the initial referral of a CYSHCN by a medical home.

**MEASURE:** The final measure will be completion of a written agreement with the following Kansas-specific interim measures:

1. Identified agencies for targeted efforts and initial meetings held to partnership and agreement
2. Obtain final agreement from partner to participate
3. Draft agreement for review
4. Agreements are vetted and signed by all parties

**DRIVERS:** Communication tools; Contract language to impact referral feedback; Privacy issues for exchange of information; Data sharing; and Training and education (includes workforce).

**Shared Resource Strategy Aim Statement:** By October 2017, families and medical home providers of CYSHCN contacting a shared resource for a needed specialist, support or service, will report that the SR was instrumental in their ability to obtain a needed specialist, support, or service in 50% of the cases.

**DEFINITION OF A SHARED RESOURCE:** The Shared Resource is a platform that provides current and well-vetted information to improve the care and outcomes of CYSHCN and their families. Information should be relevant to CYSHCN, their families and caregivers, clinicians, and service providers. The shared resource should use language

that is accessible for all, and reflect their cultural and ethnic diversity. To the greatest extent possible, the shared resource should be designed with input from families of CYSHN, clinicians and other likely users. Their continued input should be considered for ongoing direction, management, and implementation evaluation.

**MEASURE:** The Kansas-specific measure is the “Number of families of CYSHCN and medical home providers who report they obtained the requested resource, service, or information.” Kansas has defined the target population as those who contact the Kansas Resource Guide (the state’s “shared resource”) who agree to follow-up after requesting information.

In order to measure this, Kansas will track and monitor data individually around the number of families, providers, and community-based service organizations who contact the shared resource for information. This will allow the team to tailor outreach, education, and expansion efforts to meet the population most frequently utilizing the shared resource.

**DRIVERS:** Funding to support the shared resources; Community support for the shared resource; Training and education on the shared resource (includes workforce); Family engagement in creation or expansion of the shared resources; and Addressing cultural, ethnic, language, etc. barriers to accessing the shared resource.

**Cross-systems Care Coordination Strategy Aim Statement:** By October 2017, the percent of targeted CYSHCN with a Shared Plan of Care in place will increase by 20% over baseline, or, for states starting with a baseline of 0, will be 20% for the CYSCHN.

**DEFINITION OF A SHARED PLAN OF CARE:** A shared plan of care will include the information necessary to assure issues affecting a child’s health and health care are identified and accessible across systems and that activities and accountability for addressing those activities are documented. Key components included in the SPOC will be: Medical summary, family background, treating providers; Negotiated actions or plan of actions based upon the provider, patient and family’s shared goals and identified strategies; and Involvement of the family in the development of the shared plan of care.

**MEASURE:** The Kansas-specific measure is the “Number of CYSHCN with a documented shared plan of care that follow the Standards for Systems of Care.” Kansas has defined the target population as children eight through twelve who attend the KU Wichita General Pediatrics clinic with a diagnosis of ADHD (initial pilot), asthma (phase two pilot), and obesity (phase three pilot). Upon completion of the three pilot phases, it is anticipated the shared plan of care will be finalized and implemented with all pediatric patients in the clinic. Key components of this measure include tracking the shared plans of care with input from specialty care providers and the families. Additional sub-measures may be added to address individual components of the shared plan of care from the *Standards*, as appropriate and reasonable for the clinic team.

**DRIVERS:** Family engagement in Shared Plan of Care; Payer participation in Shared Plan of Care development process; Funding to support Shared Plan of Care; Training and education (includes workforce); and Agreement across two or more systems on content of Shared Plan of Care.

## ■ ■ State Plan Development Activities and Findings

### Regional Meetings

In partnership with the Wichita State University Community Engagement Institute, KS-SHCN hosted six (6) regional input meetings across the state of Kansas as part of this state planning process. The meetings were held between February 24 and April 19, 2016 in Topeka, Wichita, Pittsburg, Salina, Hoxie and Garden City. At each meeting, participants were given the opportunity to hear an overview of the KS-SHCN program and a brief overview of the *Standards for Systems of Care for CYSHCN*. Following a question and answer period, participants were then asked to discuss four standards chosen from the Medical Home and Community Based Services and Supports domains. Discussion took place in small groups and was focused on three questions:

- What is working well?
- What is missing?
- Who else needs to be involved in helping Kansas meet this standard?

*Respite Care: Health providers and plans have a system in place for ensuring timely referrals for families of Children and Youth with Special Health Care Needs with emergency respite needs.*

Representatives from across the state reported that respite care, especially on an emergency basis, is a very limited resource that is primarily available to those children and youth receiving Behavioral Health services and/or Home-Community Based Services (HCBS) through the Medicaid Waivers. In areas where the services are available, there are few qualified providers. In the Western part of the state, participants reported that many families and communities have developed a natural support system of relatives and community activities such as Mom's Day Out to provide temporary care for their children.

*Home-Based Services: Home health care is a covered benefit for CYSHCN that includes health care for the child and supportive care for the family, and is provided in the family's home by licensed professionals who have experience in pediatric care.*

Participants across the state reported that there is an effective system of care for children under the age of three years and for older children who qualify for and receive HCBS Waiver services. This system includes infant-toddler services through the education system, home health care agencies (including Local Health Departments), early childhood home visiting programs, and providers within the disability services system.

There is a reported lack of funding streams to provide similar services to older children who are privately insured or ineligible for the Medicaid waivers. Several areas of the state report there is also a lack of qualified providers and it can be difficult for families to locate staff that they trust to care for their children at home. Participants in Northwest Kansas also reported that the relatively low and fluctuating number of children in the area who require these types of services make it difficult for programs to sustain themselves.



*Pediatric Preventative and Primary Care: All children, including CYSHCN, have access to medically necessary services to promote optimal growth and development, maintain and avert deterioration in functioning, and to prevent, detect, diagnose, treat, ameliorate, or palliate the effects of physical, genetic, congenital, developmental, behavioral, or mental conditions, injuries, or disabilities.*

Providers and families from across the state reported that there is an effective network of providers from a variety of sectors that create a system of preventative care for children and their families. This system includes Local Health Departments, school and parish nursing, along with traditional health care providers. Many participants reported that screening is an available and helpful resource. Participants also cited state tracking systems such as WebIZ and EpiTrax as helping providers better identify and track local health issues and trends.

Transportation was reported as a significant barrier to accessing preventative care in every part of the state, even when the child has medical coverage. Additionally, participants reported that dental services are very limited for those children who are eligible for Medicaid or uninsured. In the more rural parts of the state, a lack of providers – especially those with pediatric training – was reported as an ongoing issue for families.

*Pediatric Specialty Care: Pediatric centers of care (e.g., cardiac, regional genetics, end stage renal disease, perinatal care, transplants, hematology/oncology, pulmonary, craniofacial, and neuromuscular) are available to CYSHCN and their families when needed.*

Specialty Clinics who provide mobile services or have satellite clinics across the state were reported to provide quality care to families who need them. However, scheduling is often a challenge and the opportunity is not available in all areas of the state.

Each region, including the more urban parts of the state, reported a limited number of specialty providers available in local areas and that families often have to travel to neighboring states to receive required care and access is limited by insurance restrictions and lack of transportation. Options for telemedicine are currently limited but seen as opportunities to improve access to care.

The full report from these meetings, outlining the participant responses by standard for each location can be found in Appendix F.

### Online Survey

In partnership with the Wichita State University's Center for Applied Research and Evaluation (CARE), KS-SHCN conducted an online survey to gain input from provider and families about how well the current system in meeting the *Standards*. The survey focused on participants' perceptions focusing on the Medical Home and Community-based Services and Supports core domains. The purpose of the survey was to gather input from service providers and consumers about how well the current system is meeting the *Standards*. The survey was anonymous, only asking the region they live in and where they receive/provide services. Additionally, we asked if the respondent was a service provider or a consumer/family member/caregiver for the purpose of identifying any differences in opinion. Ultimately, the respondents were asked to rate how well they thought the current system meets the *Standards*.

Some of the survey questions were reworded for consumers to support the varying literacy needs of those participating in the survey. The survey utilized a Likert scale (1="not well at all" to 4="very well"). In terms of meeting overall standards, the majority of participants either selected a scale of 2 ("not very well") or 3 ("fairly well"). Providers typically rated statements slightly more positively than consumers. Some of the key findings include:

#### OVERALL STANDARDS

- The majority of participants, both providers and caregivers, either "not very well" or "fairly well". Providers typically rated statements slightly more positively than consumers.

#### PLAN OF CARE

- Providers mostly chose "fairly well" while consumers typically answered "not very well" or "fairly well."

#### PEDIATRIC PREVENTATIVE AND PRIMARY CARE

- Consumers tended to answer "not very well" or "fairly well", and most providers answered "fairly well."

#### CARE COORDINATION

- Providers mostly answered "not very well" to these question while consumers were more divided between "not very well" and "fairly well" for this category.
- This is the only category in which the responses of providers tended to be more negative than those of consumers.

#### PLANS OF CARE DEVELOPMENT

- Providers mostly answered "not very well" or "fairly well" while the majority of consumers chose "not very well."

#### SPECIALTY CARE

- Consumers were slightly more negative than those from providers, however in general the responses were split between "not very well" or "fairly well".

#### AGREEMENTS BETWEEN HEALTH SYSTEMS AND AGENCIES

- The majority of providers chose "not very well" and consumers answering either "not well at all" or "not very well".

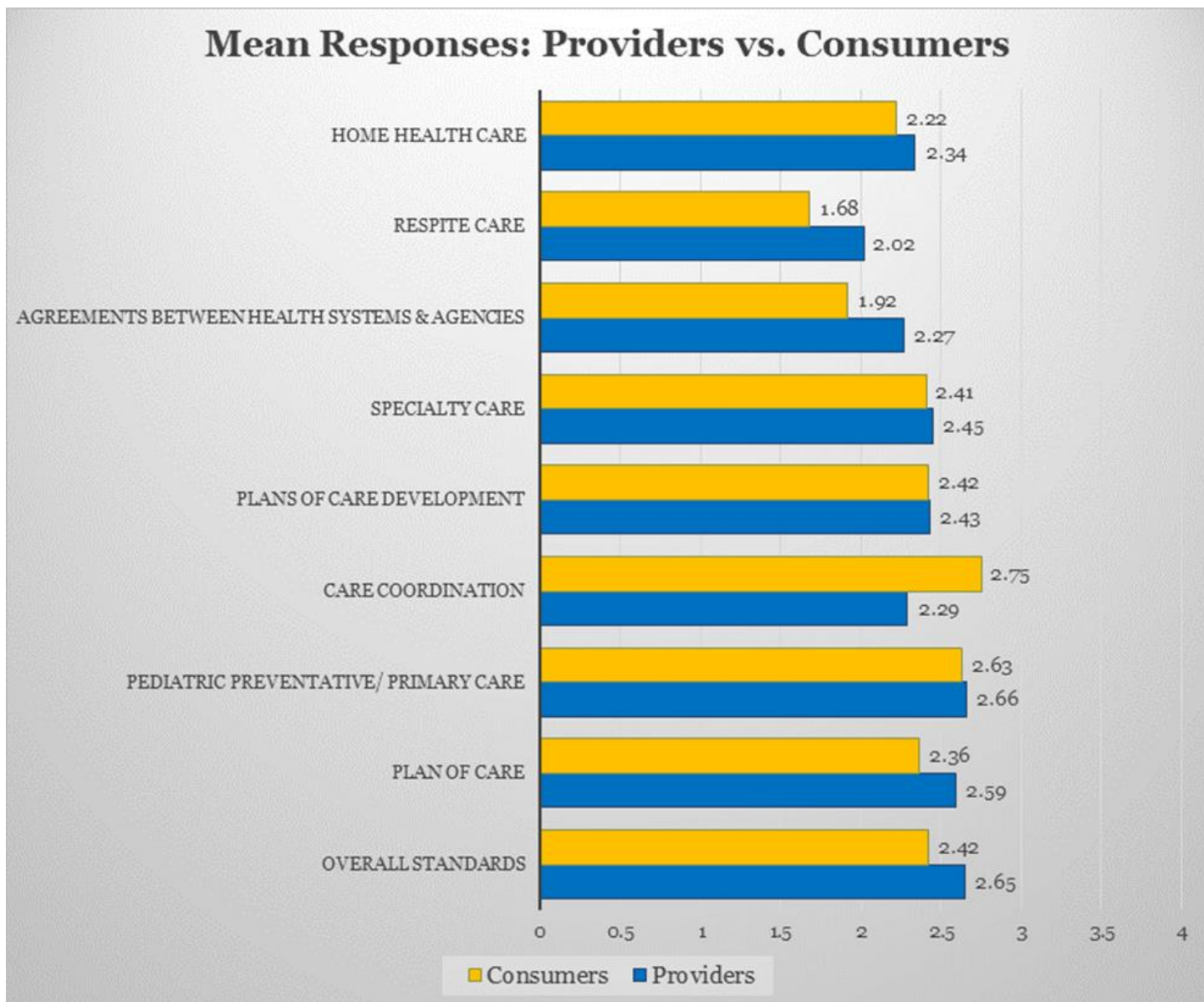
#### RESPITE CARE

- A majority of consumers (at least 60%) responded "not well at all" while providers answered slightly more positively but still primarily selecting "not very well."

#### HOME HEALTH CARE

- Responses tended to be distributed across all answer options, more so than in others.

The chart on the next page provides the specific mean responses for each section of the survey, by provider and consumer. The full report from the survey can be found in Appendix G.



## Key Recommendations

In May of 2016, KS-SHCN hosted a group of nearly 40 key stakeholders from across the state to discuss issues related to systems integration for two domains within the *Standards*. These stakeholders engaged in a reflective and participatory process that focused on the *Medical Home* and *Community-Based Systems and Supports* domains of the Standards. They were asked to review community input that was previously collected both in-person and by electronic survey; articulate a vision for success for each domain; identify potential opportunities and barriers to cross-system coordination; and discuss strategies for engaging potential partners in the integration process.

With regard to each domain, meeting participants were presented with community input regarding Kansas' ability to meet the current standards and discuss in small groups what they considered to be the most important changes that would be needed if Kansas is going to make progress on meeting these standards and where they thought new connections need to be made, based on the community's responses. Additionally, the participants were split into groups, based on the domain they felt most informed and passionate about, to discuss three questions related to cross-system coordination.

- What new opportunities exist for cross-system coordination?
- What barriers are there to cross-system coordination?
- What is the best way to engage partners?

The remaining portion of this report outlines the context in which the discussion was held, how the group defined "success" around the domain, and opportunities for cross-system coordination or collaboration.

## ■ ■ Medical Home

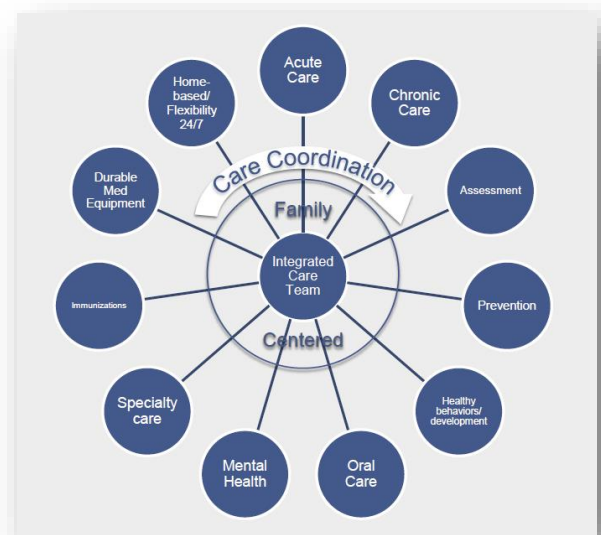
The Medical Home domain encompasses a number of services and systems including those pictured to the right.

### Defining Success

Considering the community input and the resulting conversations, participants were asked to define success from a variety of different perspectives.

For **CYSHCN and their Families**, participants stated that success would be defined as safe, effective, affordable care that would be integrated, person-centered, and easy to access. The system would be one that provides culturally responsive care that works for families – providing "carrots", not "sticks" – and allows for whole family health to be achieved. This would mean that families would be educated about the resources and the choices they offer to responsibly self-manage their care; understand their rights within the system; and trust the system to help them become functioning members of their community.

For **Providers**, the system would allow for truly patient-centered care that resulted in improved health outcomes and providers could go home knowing that they've done their jobs well. All of the "spokes" of the wheel would actually exist – achieved through community partnerships and effective inter-disciplinary teams. Providers would be part of collaborative network, one that includes health plans who trust that care providers know the patient's needs best and allows for good follow-up by providers. There would be clear expectations, reasonable caseloads, and aligned priorities among the collaborating partners. There would be a universal system of care for patients, allowing patients to access services through "no wrong door". Universal enrollment for providers in health plans



that allows for adequate reimbursement rates, reducing clinical “work-arounds” and allowing professionals to work at their best 100% of the time.

For **Referral Networks**, the group determined that success would include an easy, transparent, process that would equip and empower families to the level that they can be most successful. Resources would be available to families close to home and referral providers could count on a fiscally sound network to be available when they send families for assistance. There would be effective, bi-directional, communication and coordination amongst providers, including those who are located out of the state. For patients that require hospitalization, the process would begin with quality discharge planning and all providers would have access to an accurate and up-to-date list to make this possible. Families who enter the system are engaged and educated and providers teach them the skills they need to advocate for themselves.

### Measuring Success

Participants indicated that there are a number of existing metrics that could help progress on these efforts. These include:

- Consumer satisfaction scores
- Number of certified medical homes based on predicted population to be served
- Number of services accessed
- Number of preventative health, oral health (etc.) visits
- National survey for Children’s Health metrics
- Quantitative measures of health outcomes
- Number of Shared Plans of Care
- National Health Care Quality metrics

After reviewing information gathered from the community input sessions regarding potential partners, participants were asked to consider on whose actions success most depends. They indicated this would include families, insurers, clinicians, educators of students and health professionals, KDHE, and policy makers (including elected officials, professional associations, and foundations).

### Cross-System Coordination

Three small groups considered each question and were asked to prioritize the top ideas to share with the larger group for consideration, these are outlined below. All opportunities, barriers, and partner engagement strategies are outlined in the full report in Appendix H.

- What new opportunities exist for cross-system coordination?
  - Patient/family navigators

- Extend services geographically – telemedicine
- Reliable/dependable transportation and interpretation resources
- What barriers are there to cross-system coordination?
  - Lack of reimbursement/ coverage (medical and mental health)
  - Lack of resources, including time
  - Access to care
- What is the best way to engage partners?
  - Have a clear vision from highest level to lowest level
  - Incentives aligned – what is important to each partner
  - Get stakeholders a seat at the table – bring together small groups
  - Reimbursement/ Pay for performance (incentives)
  - Shared risk/shared responsibility/increase vesting (incentives)

## ■ ■ Community-Based Services and Supports

The Community-Based Services and Supports domain encompasses a number of services and systems including those pictured to the right.

### Defining Success

Considering the community input and the resulting conversations, participants were asked to define success from a variety of different perspectives.

For **CYSHCN and their Families**, participants stated that success would include opportunities for whole family health – families/caregivers and siblings whose physical, emotional, and social support needs are met. Families would be equipped and empowered to be responsible and successful in managing their care with increased expectations for their quality of life. There would be effective coordination and collaborations across the lifespan that includes access to qualified providers, partnerships with schools for in- and out-of-school resources and smooth transitions as needs change. When parents ask questions, they will receive clear answers and experience open sharing of information from providers that results from a person/family-centered approach to care.

For **Providers**, success would encompass the ability to share relevant information across provider networks and work within interdisciplinary teams. There would be adequate reimbursements – perhaps in the form of “bundled” billing – and billing for coordination would be an allowed expense.



For **Referral Networks**, success would include more engagement of “unusual” voices. There would be adequate resources to refer families to and these could be located through a searchable database that includes many systems of care, including access to satellite hospital/clinic services. The website might also include a centralized “help” button that contacts a trained professional that can offer personalized support and would track referrals. Ultimately, improved patient outcomes would allow programs to become more sustainable.

### Measuring Success

Participants indicated that there are a number of existing metrics that could help progress on these efforts. These include:

- “Ease of Use” framework
- Patient access to every component
- Consumer satisfaction
- Utilization of shared resource guide
- Number of enrolled, individual claims (catastrophic vs. natural progression of the disease)
- Quality of life for families
- Provider engagement reports
- Decreased healthcare costs
- ACEP.org

After reviewing information gathered from the community input sessions regarding potential partners, participants were asked to consider on whose actions success most depends. They indicated this would include families; Community Developmental Disability Organizations; Aging and Disability Resource Centers; Community Mental Health Centers; insurers; providers (including home health and intensive supports); policy makers; communities; and the lead agencies within the state, including KDHE and the Kansas Department of Aging and Disability Services. *Participants in today’s meeting noted that one key partner that might have been overlooked are local technology providers who would be instrumental in the success of efforts around telehealth.*

### Cross-System Coordination

Three small groups considered each question and were asked to prioritize the top ideas to share with the larger group for consideration, these are outlined below. All opportunities, barriers, and partner engagement strategies are outlined in the full report in Appendix H.

- What new opportunities exist for cross-system coordination?
  - Federal grant funding for system-building and federal incentives for outcomes
  - Leveraging non-traditional supports and services



- Technology/telehealth
- Education across the cross-coordination system already in place
- What barriers are there to cross-system coordination?
  - Funding for services, technology, education, training, reimbursement
  - Lack of knowledge of needs and resources
  - Language/communication barriers between patients, professionals, insurers, and clinicians
- What is the best way to engage partners?
  - Identify individual partner needs and clearly articulate how collaboration meets that need
  - Sustainable/accurate network (Database/resource network across disciplines)
  - Publicize outcomes that are encouraging

## Next Steps and Sustainability

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Staff from KS-SHCN will use the work of the stakeholders who participated in this meeting, along with the information gathered over the past few months, to identify opportunities to move the process of systems integration forward. The SHCN Program plans to hold similar processes over the next 18 months related to the remaining domains within the *Standards* to assemble a more holistic plan for systems integration.

- The second stage will begin in August and conclude in October 2016 and focus on the Screening, Assessment, and Referral and Eligibility and Enrollment domains.
- The third stage will take place February through May 2017, focusing on Access to Care, Family Professional Partnerships, and Transition to Adulthood.
- The final stage will occur August through October 2017 focusing on the final three domains: Health Information Technology, Quality Improvement, and Financing.

Partners will be asked to engage in a variety of ways to assure the overall success of the system and to improve outcomes for children and youth with special health care needs and their families.